IN THE UNITED STATES DISTRICT COURT
FOR THE MIDDLE DISTRICT OF PENNSYLVANIA

SONNY O., Jr., by his father and next friend Sonny O. Sr., DANIEL D., by his Mother and Next Friend, Nadine D., and VALERIE H., by her Mother and Next Friend, Liliyah H.,	
Plaintiffs,	Filed via ECF System
v.	Civil Action No. _____
BEVERLY MACKERETH, in her official capacity as Secretary of Public Welfare of the Commonwealth of Pennsylvania,	Class Action
Defendant.	

COMPLAINT

I. Introduction

1. Plaintiffs Sonny O., Valerie H. and Daniel D. are three young children diagnosed with Autism Spectrum Disorder (ASD). All are enrolled in Defendant's Medical Assistance (MA) program. All are in need of intensive Applied Behavioral Analysis (ABA) therapy to ameliorate their disabilities and have been unable to obtain it.
2. Defendant is responsible for the administration of Pennsylvania's MA program. Her MA program does not cover ABA therapy in a

manner that is consistent with the medically accepted standard of care, or in an amount, duration and scope sufficient to reasonably achieve its purpose of ameliorating ASD.

3. The children, through their parents and next friends, bring this action on behalf of themselves and all other similarly situated children in Pennsylvania, against the Secretary of Public Welfare, for violations of Title XIX of the Social Security Act. Plaintiffs seek appropriate declaratory and injunctive relief.

II. Jurisdiction and Venue

4. Jurisdiction is conferred upon this Court by virtue of 28 U.S.C. §§ 1331 and 1343, this being a case arising under the laws of the United States.
5. Plaintiffs' claims are authorized by 42 U.S.C. § 1396 et seq., 42 U.S.C. § 1983, and 28 U.S.C. §§ 2201 and 2202.
6. Venue is appropriate in this district pursuant to 28 U.S.C. § 1391(b)(2) since a substantial part of the events that give rise to this Complaint occurred in this district.

III. Parties

7. Plaintiff Sonny O., Jr. is a four-year-old boy from Lancaster County. Sonny has been diagnosed with ASD, is enrolled in

Defendant's MA program and is in need of ABA therapy. Through his father and next friend, he brings this suit on behalf of himself and all other similarly situated children.

8. Plaintiff Valerie H. is a five-year-old girl from Dauphin County. Valerie has been diagnosed with ASD, is enrolled in Defendant's MA program and is in need of intensive ABA therapy. Through her mother and next friend, she brings this suit on behalf of herself and all other similarly situated children.

9. Plaintiff Daniel D. is an eleven-year-old boy from Pike County. Daniel has been diagnosed with ASD, is enrolled in Defendant's MA program and is in need of intensive ABA therapy. Through his mother and next friend, he brings this suit on behalf of himself and all other similarly situated children.

10. Defendant, Beverly Mackereth, is the Secretary of Public Welfare for the Commonwealth of Pennsylvania. Defendant Mackereth is responsible to administer and oversee the Department of Public Welfare (DPW), which is the single state agency responsible for administering the MA program. Defendant Mackereth also is responsible to assure that DPW's programs and

services comply with relevant federal laws, including Title XIX of the Social Security Act.

IV. Class Action Allegations

11. Plaintiffs Sonny O., Jr., Valerie H., and Daniel D., by and through their next friends, bring this lawsuit on behalf of themselves and all other Pennsylvania children with ASD who, now or in the future, are enrolled in Defendant's MA program, and for whom ABA therapy is medically necessary.

12. The size of the class makes joinder impracticable. According to the Center for Disease Control (CDC), about one in 68 children is diagnosed with ASD. In Pennsylvania, children with significant disabilities such as ASD are eligible for Defendant's MA program without regard to their parents' income. Thus, thousands of children with ASD are eligible for Defendant's MA program. According to the CDC, "ABA has become widely accepted among health care professionals [to treat ASD]." See http://www.cdc.gov/ncbddd/autism/treatment.html (last visited June 9, 2014). It is also the *one* treatment for ASD specifically recognized by Pennsylvania statute. 40 P.S. § 764h(f)1. Thus there are thousands of MA eligible children for whom ABA therapy

would be medically necessary. Therefore, there are likely hundreds, if not thousands, of children in the class. Individual lawsuits are impracticable due to the geographic dispersion of putative class members, many of whom would lack the resources to pursue individual actions

13. There are questions of fact and law common to class members, including, but not limited to:

a. whether Defendant's MA program fails to cover ABA therapy in a manner that is consistent with accepted standards of care, and in an amount, duration and scope sufficient to achieve its purpose of ameliorating ASD; and

b. if so, whether such failure violates Title XIX of the Social Security Act.

14. The claims of the named Plaintiffs are typical of those of all putative class members.

15. The named Plaintiffs will adequately protect the interests of the class. They have no interests which conflict with other class members. Plaintiffs' counsel are experienced in litigating class actions, including enforcement of Title XIX of the Social Security Act.

16. Defendants have acted or refused to act on grounds generally applicable to the class, thereby making appropriate injunctive and declaratory relief with respect to the class as a whole.

V. Facts

A. The Medical Assistance Program

17. Title XIX of the Social Security Act (Title XIX), 42 U.S.C. § 1396 *et seq.,* establishes the federal MA program.

18. MA is a cost-sharing arrangement under which the federal government reimburses more than half of the expenditures incurred by states that elect to furnish MA to eligible individuals.

19. States are not required to participate in the MA program but, if they choose to do so, they must comply with Title XIX and its implementing regulations. Pennsylvania has chosen to participate in the MA program.

20. One purpose of Title XIX is to enable each State to furnish rehabilitation and other services to help families and individuals attain or retain capability for independence or self-care. 42 U.S.C. § 1396-1.

21. Each Medicaid service offered must be sufficient in amount, duration and scope to reasonably achieve its purpose. 42 C.F.R. § 440.230(b).

22. Title XIX mandates that a state MA program cover certain specified health care services. See 42 U.S.C. § 1396a(a)(10)(A). For persons under 21, those services include Early and Periodic Screening, Diagnosis and Treatment (EPSDT), which is defined to include all "necessary health care, diagnostic services, treatment, and other measures described in section [1396d(a)] to correct or ameliorate defects and physical and mental illness and conditions." See 42 U.S.C. § 1396d(r)(5).

23. Among many other things, services described in section 1396d(a) include "any medical or remedial services (provided in a facility, a home, or other setting) recommended by a physician or other licensed practitioner of the healing arts within the scope of their practice under State law, for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level," and "medical care, or any other type of remedial care recognized under state law, furnished by

licensed practitioners within the scope of their practice as defined by state law." See 42 U.S.C. § 1396d(a)(13)(C) and (6).

24. Pennsylvania has further defined what it means for a covered service to be medically necessary for an individual recipient, as follows:

> A service, item, procedure or level of care that is necessary for the proper treatment or management of an illness, injury or disability is one that:
>
> (1) Will, or is reasonably expected to, prevent the onset of an illness, condition, injury or disability.
>
> (2) Will, or is reasonably expected to, reduce or ameliorate the physical, mental or developmental effects of an illness, condition, injury or disability.
>
> (3) Will assist the recipient to achieve or maintain maximum functional capacity in performing daily activities, taking into account both the functional capacity of the recipient and those functional capacities that are appropriate of recipients of the same age.

55 Pa. Code § 1101.21a.

B. Applied Behavioral Analysis (ABA)

25. ABA is a nationally recognized, evidence-based, treatment for ASD.

26. According to Pennsylvania law, ABA means "the design, implementation and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior or to prevent loss of attained skill or function, including the use of direct observation, measurement and functional analysis of the relations between environment and behavior." 40 P.S. § 764h(f)(1).

27. In children with ASD, ABA is a treatment method to enhance functional communication, social interaction, and other life skills, and to eliminate negative or destructive behaviors.

28. The generally accepted medical standards provide that children with ASD who exhibit significant skill deficits and/or inappropriate behaviors in multiple domains (e.g., cognitive, communicative, social, adaptive…) should typically be provided at least 25- 40 hours of intensive intervention as soon after initial diagnosis as possible, and that these services should continue for at least six months and then be reassessed based on the individual child's

response to the intervention. For children with ASD who exhibit less significant deficits, smaller amounts of ABA, targeted to their specific deficits, are recommended.

29. The generally accepted medical standards provide that ABA therapy should be planned and overseen by a Board Certified Behavior Analyst (BCBA), which is a Masters or PhD level clinician with additional approved training, classwork and/or experience in providing ABA, who has passed an exam by the Behavior Analyst Certification Board (or an individual with a license in a related field), who has experience in providing ABA to children with ASD, and carried out by trained paraprofessionals.

30. Pennsylvania has also created a license for Behavior Specialists who are Masters level clinicians who have received specified autism-related training. 49 Pa. Code § 18.521 et. seq.

31. Under Pennsylvania law, the scope of practice of licensed behavior specialists includes the design, implementation and evaluation of behavior modification intervention components of treatment plans, including those based on ABA. 40 P.S. § 764h(f)(4).

32. For a large percentage of young children treated with ABA, their ASD is significantly ameliorated by the treatment, not just for the duration of the treatment, but for their lives.

C. <u>ABA and Defendant's MA program</u>

33. Defendant's MA program does not provide ABA as a distinct service.

34. Defendant's MA program provides a set of services called Behavioral Health Rehabilitation Services (BHRS), which are home and community based behavioral interventions for children with mental health disorders.

35. While Defendant provides BHRS to many children with ASD, these services are not designed to treat developmental or neurological disorders, such as ASD.

36. There are multiple autism service providers in Pennsylvania that provide ABA services under the supervision of BCBAs and/or licensed behavior specialists, but which do not meet requirements to be enrolled as BHRS providers in Defendant's MA program.

37. These autism service providers provide ABA services to children with private insurance or through private pay, or in some

cases, through school districts or Early Intervention programs, but cannot bill Defendant's MA program.

38. BHRS are overseen by Defendant's Office of Mental Health and Substance Abuse Services (OMHSAS), which sets standards for services and providers and approves BHRS service descriptions.

39. BHRS can include the services of a Behavioral Specialist Consultant (BSC) to assess the needs of a child with behavioral disorders and develop an intervention plan, and a set number of hours per week of Therapeutic Support Staff (TSS) to provide one-to-one interventions.

40. While Defendant allows TSS interventions to address some of the behavioral *symptoms* in children with ASD, she does not allow interventions to correct or ameliorate the underlying developmental or neurological deficits of children with ASD.

41. OMHSAS has developed criteria, commonly referred to as "Appendix T", for the authorization of BHRS services.

42. Appendix T criteria are based on the extent of emotional and behavioral disturbance a child with a mental health diagnosis exhibits, and the risk of out-of-home placement.

43. The Appendix T criteria are not designed to determine the need for, or the amount, duration or scope of, ABA.

44. Defendant does not use criteria that assess the intensity of treatment needed to maximize a child's functional abilities relative to their age, or use any of the criteria for authorization of services that have been developed by professionals in the field of ASD.

45. Defendant does not require BHRS agencies that provide services to children with ASD to employ anyone with expertise in ABA.

46. Defendant will not permit enrollment of licensed BSCs in the MA program unless they have a service description, which is a detailed document describing the treatment methods used, the population served, and many other components, approved by OMHSAS.

47. OMHSAS has told BHRS providers that BSC services for children with autism cannot be aimed at increasing independence and self-care skills.

48. OMHSAS has told BHRS providers that they cannot bill for the provision of "habilitation" services. OMHSAS did not define that term.

49. OMHSAS has told providers that they cannot bill for providing personal care services, which includes cuing and prompting a child to perform basic activities of daily living, such as dressing and toileting.

50. Defendant's Bureau of Autism Services has stated that BHRS is not a good fit for individuals with ASD.

51. BHRS are funded through Defendant's Office of Medical Assistance Programs directly or, more frequently, through Behavioral Health Managed Care Organizations (BH-MCOs) under contract with the counties which are themselves under contract with DPW.

52. BH-MCOs require children needing BHRS to use providers who are in their networks.

53. BH-MCOs have told ABA providers that, even if they could enroll in MA, they cannot enroll in their networks because they have enough BHRS providers, even when they do not have a sufficient number of BHRS providers that employ BCBAs or have any expertise in ABA therapy.

54. Prescriptions for BHRS are not consistently reviewed for authorization purposes by physicians or psychologists who have expertise in ASD.

55. Defendant and her BH-MCOs have been denying prescriptions for TSS services for children with ASD who do not have significant negative behaviors regardless of the need to treat and ameliorate the ASD itself.

56. Defendant and her BH-MCOs have been limiting the amount of TSS services to those children who do have "negative behaviors" to an amount that is below the generally accepted medical standard for ABA treatment.

Sonny O.

57. Sonny O. is a four-year-old boy who lives in Lancaster County, Pennsylvania.

58. Sonny is enrolled in Defendant's MA program, and receives his behavioral health services through Community Care Behavioral Health (CCBH), one of Defendant's contracted managed care organizations.

59. Sonny is non-verbal, engages in problematic and self-injurious behaviors, and requires constant supervision.

60. In August of 2012, when he was two and a half years old, Sonny was diagnosed with ASD and Attention Deficit Hyperactivity Disorder by a licensed psychologist employed by Philhaven Center for Autism and Developmental Disabilities (Philhaven), one of a few BHRS providers which has expertise in ABA.

61. The evaluator recommended that Sonny receive BHRS "consisting of an ABA-based, Verbal Behavior model approach designed to facilitate expressive language, develop more appropriate play and social skills, and foster the acquisition of early learning skills."

62. Shortly thereafter, Sonny began receiving twenty hours per week of ABA therapy from Philhaven.

63. His goals included: 1) increasing his ability to ask for what he wants, rather than engaging in problematic behavior to obtain things; 2) increasing his ability to express himself verbally in general, including repeating verbal statements and labeling items in his environment, in order to engage in shared social interactions; 3) increasing his ability to respond to other people's verbal behavior, in order to engage in shared social interactions.

64. Each of these goals was paired with specific interventions and

measurements for progress.

65. In November of 2012, after only a couple months of ABA therapy, the team from Philhaven informed Sonny's family that they could no longer provide their ABA services to any children funded through MA.

66. Philhaven reported to the family that DPW had audited their program and determined that the ABA services that Philhaven had been providing to Sonny and other children with ASD could not be billed to Defendant's MA program.

67. Philhaven also reported to the family that, under their approved service description, DPW would no longer permit them to provide any services to children under the age of three.

68. Sonny's services were stopped altogether from that date until his third birthday in February of 2013.

69. When Sonny turned three, Philhaven developed a new treatment plan for Sonny, and began providing ten hours per week of TSS services and twelve hours per month of BSC services.

70. The services are less intensive and less structured than the ABA services he had been receiving, and are limited to the goals of eliminating his problematic behaviors.

71. For the new services, Sonny's treatment goals were changed to: 1) decreasing his frequency of physically aggressive behaviors; and 2) decreasing the duration of his crying and yelling.

72. The interventions changed as well. While his BSC/TSS continue to teach him to ask for things, rather than engage in problematic behaviors, they no longer work on his skills related to expressive and receptive language in general, such as labeling objects in his environment or responding to questions.

73. The services have become reactive, rather than proactive. Much of the time his TSS has to wait for him to misbehave in order to intervene. Rather than working on skill development, the focus is on his bad behavior.

74. Sonny's services are no longer designed to "facilitate expressive language, develop more appropriate play and social skills, and foster the acquisition of early learning skills", as prescribed by the psychologist.

75. Sonny also receives Early Intervention services from the state education system, but these services are not sufficient to treat his ASD.

76. Sonny's family is very concerned about the lack of progress he is making in ameliorating his ASD and in achieving his maximum functional capacity relative to his age.

Daniel D.

77. Daniel D. is an eleven-year-old boy from Pike County, who is enrolled in Defendant's MA program.

78. Daniel is not enrolled in a managed care plan. Rather, his services are funded directly by Defendant through the MA fee-for-service system.

79. Daniel was diagnosed with ASD when he was two and a half years old.

80. As a result of his ASD, Daniel has self-injurious behaviors which have required arm guards and a helmet. He displays significant physical aggression towards others, has a lack of safety awareness, will climb on furniture and objects despite safety risks and elopes. He is not toilet trained and smears his feces. He has significant delays in expressive and receptive language. He displays self-stimulatory behaviors. He has Pica and will attempt to eat inedible objects. He also has rumination disorder,

regurgitating eaten food throughout the day. He has difficulties with social interactions.

81. Based on the generally accepted standard of care in the field of ASD, Daniel is a child for whom twenty-five to forty hours of ABA therapy should have been prescribed and provided at an early age.

82. ABA therapy could have addressed not only his aggressive behaviors and social deficits, but also his skill deficits related to communication, toileting, eating and safety.

83. Instead, because ABA is not a recognized MA service, Daniel was referred for BHRS services.

84. Daniel's BHRS treatment plan does not consist of ABA therapy.

85. Most recently, Daniel's BHRS prescriber submitted a request to OMHSAS for twenty hours per week of TSS services during the school year and thirty-five hours of TSS services during the summer so that his behaviors could be addressed in the context of interacting socially with children his age in summer camp.

86. Applying Appendix T, OMHSAS authorized only fifteen hours per week of TSS through May of 2014, and ten hours a week thereafter.

87. With only ten hours per week of support, Daniel would not be able to go to summer camp and have the needed experience of interacting with other children in a social environment.

88. Daniel's family appealed the denial of the requested TSS hours and the administrative law judge found in his favor.

89. OMHSAS has now requested reconsideration of the decision explaining that "TSS services are behavioral services that are not able to meet Daniel's needs." Application for Reconsideration, Case Number 520022355, dated May 23, 2014, at page 3. (Attached hereto as Exhibit A.)

90. According to OMHSAS's reconsideration request, the reviewing psychiatrist for OMHSAS stated at Daniel's appeal hearing that "Daniel's issues with regurgitating his food and eating non-food items are not behavioral disorders." Application for Reconsideration at page 4. She also stated that, "Daniel was unable to attend summer camp in 2013 because TSS workers cannot provide assistance with toileting and activities of daily living which Daniel needs." Id. at page 3.

91. Working on core skills like toileting and proper eating are legitimate components of ABA therapy.

92. Unfortunately, instead of offering ABA therapy, OMHSAS argued that "Daniel's needs are primarily for assistance with activities of daily living and safety issues, which … are needs that a home health aide could meet." Id. at page 4.

93. Home health aides have no training in ASD, ABA, or any form of therapy. While they provide "assistance" with toileting and activities of daily living to people who are unable to accomplish these tasks for themselves, they do not provide training in these, or any, areas.

94. If the Defendant covered ABA as a service distinct from BHRS, and in the appropriate amount duration and scope, Daniel's ABA provider would be better able to address all of Daniel's behaviors and skill deficits.

95. Daniel's school program incorporates some ABA principles, but it is not sufficient to treat his ASD.

96. Based on the generally accepted standard of care in the field of ASD, Daniel continues to be in need of intensive ABA therapy.

97. While nine years later than originally needed, Daniel is still entitled to receive intensive ABA services, in an amount, duration and scope reasonably sufficient to ameliorate his ASD as much as

possible, and to maximize his functional capacity relative to his age.

Valerie H.

98. Valerie H. is a five-year-old girl from Dauphin County who was diagnosed with ASD in April of 2012.

99. She is nonverbal, does not interact with peers and has limitations in communication, socialization and self-care. In addition, she engages in repetitive behaviors, such as rocking, staring into space and running back and forth.

100. Valerie is enrolled in Defendant's MA program and receives her services through Perform Care, one of Defendant's contracted MCOs.

101. Valerie also has insurance (TriCare) through the military.

102. In March of 2013, Valerie's pediatrician prescribed ABA therapy, and her mother sought out services for her from both TriCare and MA.

103. TriCare authorized twenty hours of ABA therapy for Valerie, to be provided by a BCBA employed by Autism Services North (ASN), the ABA provider in their network.

104. Under TriCare, the family was responsible to pay a co-payment which, in 2013, was twenty five dollars for each hour of service.

105. Because MA did not cover the services of ASN, it did not cover the co-payments, and the family could not afford to pay the co-payments for twenty hours of therapy per week.

106. Instead, Valerie began receiving four and a half hours per week of ABA services from ASN.

107. In the fall of 2013, Defendant's MA program authorized BHRS services, including a BSC and twenty hours of TSS, to be provided by a licensed BHRS agency.

108. The BHRS agency's treatment plan did not include ABA.

109. The treatment plan did not address communication skills, or other self-care skills other than safety.

110. The treatment plan focused exclusively on behaviors and safety.

111. The treatment plan employed methods that are not appropriate to a child with Valerie's significant degree of Autism and developmental delay.

112. The TSS from the BHRS agency was not trained to provide ABA.

113. The services provided by the BHRS agency were nothing like the ABA services provided by ASN.

114. In October of 2013, a behavioral and developmental pediatrician, recommended that Valerie receive between twenty and forty hours per week of ABA therapy.

115. Valerie's mother asked Valerie's TSS if she could provide ABA, but the TSS said that she was not allowed to perform ABA therapy and that no one at her agency was licensed to perform it.

116. Valerie's mother discontinued the TSS services in April of 2014 because they did not seem to be helping her.

117. The BHRS services were not effective in ameliorating Valerie's ASD or maximizing her functional capacity relative to her age.

118. In May of 2014, TriCare lowered the co-payment amount and Valerie's mother is now paying for six of the 20 prescribed hours of ABA therapy for her.

119. Despite the small number of hours, Valerie's mother has seen some positive effects on Valerie from the ABA services she receives from ASN, but it is not enough to meet her needs.

120. Valerie is also receiving Early Intervention services from the state education system, but they are not adequate to treat her

ASD.

121. Valerie is still in need of, and not receiving, intensive ABA therapy for at least twenty hours per week.

VI. Claim

A. Violation of Title XIX of the Social Security Act - Failure to Provide EPSDT Services

122. Paragraphs 1 through 121 are incorporated by reference.

123. Title XIX of the Social Security Act requires that states participating in the Medical Assistance program must make Medical Assistance benefits available. 42 U.S.C. § 1396a(a)(10)(A). For persons under 21, this includes providing or arranging for the provision of Early and Periodic Screening, Diagnostic and Treatment ("EPSDT") services. 42 U.S.C. § 1396a(a)(43)(C).

124. EPSDT services include services that are necessary to correct or ameliorate “defects and physical or mental illnesses or conditions.” See 42 U.S.C. § 1396d(r)(5) and § 1396d(a).

125. Specifically, EPSDT services include “medical care, or any other type of remedial care recognized under state law, furnished

by licensed practitioners within the scope of their practice as defined by state law." See 42 U.S.C. § 1396d(a)(6).

126. ABA is recognized under state law and is within the scope of practice of licensed behavioral specialists. 40 P.S. § 764h(f)(1) and (4).

127. EPSDT services also include "any medical or remedial services (provided in a facility, a home, or other setting) recommended by a physician or other licensed practitioner of the healing arts within the scope of their practice under State law, for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level," 42 U.S.C. § 1396d(a)(13)(C).

128. ABA therapy is a covered EPSDT service.

129. Defendant is failing to offer ABA therapy to Plaintiffs and class members in an amount, duration and scope sufficient to reasonably achieve its purpose of ameliorating their ASDs.

130. Defendant has failed to make available the EPSDT services to which Plaintiffs and class members are entitled, in violation of 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43)(C), and 1983.

VII. Relief

131. Plaintiffs respectfully request that the Court award the following relief:

i) exercise jurisdiction over this action;

ii) certify this case to proceed as a class action pursuant to Fed. R. Civ. P. 23(b)(2);

iii) issue appropriate declaratory relief and injunctive relief; and,

iv) grant such other relief as may be appropriate, including awarding reasonable attorneys' fees, litigation expenses, and costs pursuant to 42 U.S.C. § 1988.

Respectfully submitted,

Dated: June 9, 2014 By: s/ Rachel Mann

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